

The Division of Mental Retardation and Developmental Disabilities' System Breakthrough for Excellence

Acknowledgement and Summary of Public Comments

On behalf of the many participants in the System Breakthrough for Excellence (SBE) customer-satisfaction project, "the Division would like to express appreciation for the responses received during the public comment period.

During the public comment period, the "System Breakthrough for Excellence" report was presented to various advocacy groups, provider agencies, people involved in the development phase of the report, and staff to solicit input. A list of questions was attached to the report to aid people in responding to the draft SBE report.

The Division of MRDD has sent letters of thanks acknowledging the responses to the individuals, agencies and organizations that responded and provided a return address.

In this document, the Division of MRDD has listed individual comments and summarized more lengthy responses from two agencies. Many responses support the initiatives; other submissions present opportunities for the Division to build and strengthen upon existing relationships and communication with those agencies.

Next Steps

A second document annotating progress under each of the eleven Initiatives and Recommendations is being prepared. This document, "Progress Report—System Breakthrough for Excellence," will attempt to answer questions that may be posed by readers and participants well as serving as an update for the many interested parties. Both the "Acknowledgement and Summary of Public Comments" and "Progress Report—System Breakthrough for Excellence" will be e-mailed to existing distribution lists and posted on the DMH web-site (www.dmh.mo.gov).

The purpose of reporting on each phase of the System Breakthrough for Excellence is to inform consumers, families, advocacy groups, provider agencies, and staff of the project status and continue dialogue with our stakeholders.

Initiative and Recommendation #1: Individual Budgets for Consumers

From the Report

"Improved access for all persons to their budget using a web-based system and pilot sites for individuals in conjunction with the *Independence Plus* grant."

"This initiative's goal will result in a self-directing budget process, a service delivery approach that combines the principles of individual choice, control, and independence with personal decision-making and responsibility."

Summary of Individual Responses

- I am interested in the individual budget idea.
- Need a "menu" for families.
- Give families a set budget but let them choose services most important to them.
- [This initiative will increase consumer choice and control] through individualized and personalized budgets and plans.
- Yes! [Access to services] is a problem in rural areas, with a lack of providers. Ex. McDonald, Dade, and St. Clair counties.
- Yes! Families/self-advocates will be happier and they will do it with less expense.
- Yes! Competence will be rewarded!
- Communication is improved by the Agency down to the ones being served.
- Regional Center staff don't always know the resources of the community. You may need a Broker with a list of providers on it. However, choice is a must for the Consumer.
- Allow friends to be the provider for the customer.
- Offer lots of training and information to providers and customers.
- There really isn't any more control for consumers when they are still limited to who they can choose.
- If family members can give quality care they should be able to get paid too.
- [The initiative will improve access to services] if family members get involved. Families are not being offered choices – client is having to ask for specific services.
- Case managers – let consumers choose what is available. Tell families what is out there – don't have families guessing.

Initiative and Recommendation #2: Statewide Rollout of System of Care Model

From the Report

"For services to be effective and cost efficient, they must be provided within a *System of Care* that unites planning and funding from all child-serving agencies.

"Missouri's goal is to expand services that will enable a child to stay in their home and organize those services in a comprehensive system that will 1) provide an effective "single point of entry" regardless of how the child first contacts the system; 2) provide as continuum of effective services; and 3) blend disparate funding streams to support the system."

Summary of Individual Responses

- I strongly support one application and one plan!
- Continue to strengthen partnerships with other state agencies
- We need to be able to go from agency to agency without repeating the problems each time.
- Communication between [agencies] is the key.
- HIPPA is hindering the process of helping those who need it.
- Agencies need to be able to work together to provide necessary services to consumers so resources can be used more efficiently.
- Roll out the programs as intended [to improve access to services].
- I hope all of this applies to the boonies as well as the townies and cities.
- Yes, with other groups working together, information is passed around.
- The need for an integrated support system is nothing new. We constantly struggle with realigning the social support systems with the needs of modern America.
- A growing number of Americans with disabilities need an easy access to a broad array of high quality services ad supports that seek to prevent, as well as treat their problems and recognize the interrelationships among our social service, Mental Health, education, vocational, and health systems.
- Too many people are lost in a catch-as-catch-can non-system of public and private service.
- Schools, DFS – a generic application for services.
- Good communication between all agencies and families.
- I sincerely hope that the division will do pilots in each region with as many of the 11 recommendations as possible.
- Access is critically needed in each Regional Center whether it is one unit in each Habilitation Center or a small contract with private community based acute programs.

- MRDD kids are often denied from private acute hospitals and are sent to State psychiatric facilities that are not specialized nor trained in serving this population. This is a critical need in the State.
- We have dramatically increased the amount and type of supports that can be provided but have not integrated the delivery system to make the services and supports available to individuals in need.
- Systems collaboration has been discussed for many years and is not something we need to “invent.”

Initiative and Recommendation #3: Standardize Formula for Size and Composition of Caseloads

From the Report

"Access to Service Coordination, Specialized Service Coordinators, Reducing Caseloads, Enhanced Competence of Staff"

Summary of Individual Responses

- Standardization of caseloads would be wonderful. When will it happen?
- How do you expect to standardize case loads when you keep doing away with case workers? They have too big of a load already.
- Retention of case managers is needed.

Initiative and Recommendation #4: Service Coordinators Competencies and Training

From the Report

"As part of the Division's 'Framework for Consumer Safeguards and Quality Outcomes', it will design a quality assurance system to determine if personal plans are effectively addressing the needs, preferences, goals (including future needs) according to the Person-Centered Guidelines and the Division's Quality Outcomes document."

"A comprehensive standardized training package for supervisors must include not only the "how-to's" that Case Managers must know, but also supervisory skills, coaching skills, administrative skills, and cultural competencies. They must also be knowledgeable of system-wide issues and trends they may encounter"

Summary of Individual Responses

- Better training of case managers [is needed to improve access to services].

- Utilize outside resources rather than train staff to implement services provided by other agencies/resources.
- Better training at the different agencies [will improve access to services].
- Again, training for those who should be implementing [will enhance competencies and information].
- Yes, [the initiatives] definitely support the effort to standardize trainings and documentation – we need to stop "reinventing the wheel."
- Consistency in training for service coordinators is essential.
- Yes, [the initiatives will improve access] some, but to really improve access would be to allow the case workers to make suggestions as to what services would help.
- Yes, better training would help the case worker if she will be able to share the information freely.
- Release case workers to share what they know without the client having to ask when the client doesn't know and is asking for help.
- Yes [the initiatives will enhance competence and information because] there is training for case managers and cuts lots of "red tape."
- The plan increases competency training and information to Regional Center workers. Cross agency training and youth specific training will also enhance employee ability to better serve our customers.

Initiative and Recommendation #5: Stabilization Unit

From the Report

"A stabilization unit for youth at Bellefontaine Habilitation Center to work with adolescents. This unit's purpose is to give adolescents with behavioral issues an environment that addresses their behavior in a therapeutic environment. The goal of this unit is to stabilize the person for a successful transition back to the community as agreed upon by the family member or guardian."

"Stabilization Units for Adults...could provide a secure setting with specially trained crisis staff to provide crisis support, medication review, and positive behavior supports. The purpose of the unit is to stabilize the individual so that s/he can return home or to their community living arrangement safely, with individualized supports, as quickly as possible."

Summary of Individual Responses

- Need more than one pilot for children's stabilization in St. Louis.
- I am particularly pleased with the attention given to crisis stabilization.

Initiative and Recommendation #6: Access to Information in Easy to Read Format, through Internet

From the Report

"Information on licensure and certification to be posted on the DMH web site."

"Data collected through service coordination monitoring, personal health audits, health inventories and nursing audits, consumer and family member quality assurance visits, fiscal audits, mortality reviews and certification surveys that impact health and safety will be input [into a web-based data system]. Also complaints will be tracked. Utilizing the information ...will assist the state in identifying where prompt system changes are needed to enhance consumer outcomes."

"Community Connections web site...includes information from local communities, including programs, providers of services, and links to appropriate resources."

Summary of Individual Responses

- [The initiative will enhance competence and information] if all information is accessible to all consumers.
- [Consumer choice and control can increase if] better information is available to the consumer.
- Does everyone have a computer?
- Does everyone know how to use a computer?
- I can see how this will help [increase consumer choice and control for] those who use the Internet.
- This will help [enhance competence and information for] those who use the internet.
- Getting the word out is important. How do you do that locally? A one time mass mailing is not going to do it.
- Why not use SB40 Boards and Regional Councils to assist U.M. Extension Service. The community connections updated by U.M. Extension Service is not all that complete.
- [The initiatives support the work of the workgroups, etc.] to a small degree. This will help agencies and providers overall more than consumers.
- Will consumers be offered training and assistance on internet access? We need to identify to consumers exactly where they can access this info.
- [Access to services can be improved through] a variety of methods to get info to consumers – not everyone has a computer or [is] adept in accessing information.
- [This initiative will] not necessarily [increase consumer control or choice]. Provide more information – yes.

- Internet access 24 hours each day is great. What about people with no internet and/or have trouble getting to the internet?
- Give us access to plans 24 hours a day.
- By expanding on existing procedures, documents, and policies and bringing political “clout” to the different agencies of government the ability providing a single source document for all agencies, available 24 hours a day, and driven by the consumer can be completed within twenty-four months. The Interagency Planning and Support project which was funded from 1997 through 2001 by the U.S. Department of Education, Office of Special Education Programs has laid the groundwork and shown the practical application of a single source document.

Initiative and Recommendation #7: Direct Care Worker Competencies and Training

From the Report

"The Division proposes to create a competency-based system for direct care staff, case management staff, and supervisory staff. Four components to be included are 1) Formal; 2) Hands on application; 3) Individual on-site professional clinical mentoring; and 4) continuing competency."

"The purpose of the [Community Direct Care Worker Grant Application] will be to improve the ability of individuals and providers to recruit and retain community direct care staff."

Summary of Individual Responses

- Competency standards for direct care staff and service coordinators manual should help!
- This is the best part of the system breakthrough.
- Do this if this is the only one that can be done, as it could make the biggest difference. However, do it right and don't go the cheap route.
- Better pay for home aides.

Initiative and Recommendation #8: Partners in employment Project

From the Report

"This initiative will focus on supporting and tracking pilots that offer great promise for readying individuals for supportive or competitive employment. They will include collaboration on both the state agency and community level."

“The Department’s values speak of community integration and self-determination, which includes striving for a ‘living wage’.”

Summary of Individual Responses

- Yes [this initiative will increase consumer choice and control]. Use of PASS in employment – great! Person Centered Planning!
- Already a system in place of service providers for employment issues and their success rates.
- VR [Vocational Rehabilitation] has been working under the “Informed Choice” model for the past few years.
- Is the employment coordinator a “qualified rehabilitation professional”? If not – should refer to agency where they are “QRP” – VR.
- Why expend MRDD’s limited funds on a program when there is another state program in place with 80 years experience in employment for MRDD population?
- Duplicating services that are available from VR.
- Improve access to services? Maybe! Increase consumer choice and control? Hopefully!
- I believe the considerations stated on page 29 show some of the problems. I see lots of excuses from agencies. I believe we need to change funding for results.
- Put money into the hands of the consumers (vouchers) which would save the state money. The only ones getting jobs are the staff of vendors and VR.
- Teach and train consumers about their choices and control.
- I noticed that the St. Louis area is not included on a school and employment project. As a representative from St. Louis we would like to be included.
- I am concerned (pg. 16) about some pilot programs and collaborations with Rehabilitation Centers in developing SE (supported employment) opportunities on campus. Once again the rehab center supports the end versus the consumer selecting the SE agency. Another concern – Senate Bill 40 Boards operate differently in each region.
- I am particularly pleased with the attention given to the transitional youth.
- Better collaboration with other agencies already doing what needs to be done regarding jobs, i.e. voc rehab. Resources are too limited to be stretching them so thin.
- In many cases, parents are having to quit work to care for their child once he/she graduates from school. Especially if these individuals require the support offered by a day program. These programs are very expensive to pay for out of pocket and many families are unable to afford it.

Initiative and Recommendation #9: Family and Consumer Support

From the Report

“Beginning immediately, the Division will continue working closely with the Missouri Planning Council for Developmental Disabilities and the University of Missouri – Kansas City Institute for Human Development to target the use of the [Missouri DD Resource Center] as the main referral point for the citizens of Missouri to become informed and empowered by information relevant to their needs.”

“It is agreed that the continuation of [the Parent Policy Partners] in each of the regional centers is essential.”

Summary of Individual Responses

- Would be great to involve the families more.
- Some training for parents on the importance of discipline is needed extremely bad. Many parents are at a loss on how to train child so it can function in society when possible.
- I wish pamphlets, brochures could be sent to every first time parents without scaring the crap out of them.
- Would be great but in the country not everyone has a computer or even access to them.
- [Would improve access to services] if implemented in its entirety.
- [Access to services can be improved by] letting people know what is available. Advertise more.
-

Initiative and Recommendation #10: Study Possibilities of Expansion of Crisis System

From the Report

“The Division of Mental Retardation and Developmental Disabilities will study the possibilities of collaboration between the of Comprehensive Psychiatric Services and Alcohol and Drug Abuse Divisions and the MRDD system of Behavior Resource Teams and other crisis and emergency systems. In addition, the Division will explore the availabilities of local, community-based providers to expand this service on a statewide basis.”

Summary of Individual Responses

- I am particularly pleased with the attention given to the MRDD crisis system.
- I have not been aware of any crisis intervention system with the Division of MRDD and behavior teams have been eliminated from most Regional

Centers. It is critical for MRDD to develop or collaborate with existing DMH ACI systems for children and youth. Again, these children are either denied critically needed stabilization services or are misdiagnosed and receive harsh, perhaps inappropriate services. Trained, specialized crisis intervention services are needed.

Initiative and Recommendation #11: Development of Performance Measures

From the Report

“State agencies must develop and implement a performance-based budgeting system that establishes goals and objectives, provides detailed measures of program and fund performance against attainment of planned outcomes, and provides for program evaluation.”

Summary of Individual Responses

- [The initiatives will] possibly [improve access to services]. Will there be someone checking to see if this is being done.
- [The initiatives will] possibly [increase consumer choice and control] if there is a way to make sure the initiatives are carried out.
- [The initiatives will] possibly [enhance competency and information]. Will there be accountability in getting these common sense ideas across all agencies?
- This will be good if it will be implemented as it is written.
- [The initiatives will improve access to services] if administered correctly and as intended.
- Ensure the services remain intact so consumers are not losing choices due to no services available.
- The ideas seem to be directed toward positive outcomes. Follow through!
- The “System Breakthrough of Excellence Report” is an excellent document that focuses on a direction to change our support system. Unfortunately, I have seen many excellent documents that subscribe to systematic change and collaboration that never result in any real directional shift. The real test is whether we can sustain the goals of this document in the highly vital political and economic environments of our state.
- I know that there are some very thought provoking and innovative goals that will be hard to implement with the staff constraints.
- I believe that the pilots must be reported to MACDDS and MO anchor organizations frequently to allow individuals to know that there is some forward movement!
- These are good ideas but unless they are funded they mean nothing.

The following section is a listing of broad-ranging comments that were submitted to the Division:

In response to the question, “Do the initiatives support the work of the workgroups, focus groups, and the voice of the consumer?” the following comments were received.

- Yes, I believe so
- If implemented and accessed.
- Yes!
- To a small degree. This will help agencies and providers overall more than consumers.
- I felt the work in focus groups was important. But I found the final product difficult to understand and identify the end result of recommendations that the committee I served on. After a variety and layers of filtering the message of the group gets lost. I found the final report difficult to read.
- A lot of money is being spent for committees to come up with ways to help families and they should use the money for the families themselves.
- Only if top level (keep at a minimum) personnel do their job by keeping paperwork at a minimum and making sure adequate funding is available.
- I was not a participant of the work or focus groups. I do feel the initiatives do support the needs of consumers, consumers defined in the children’s world as families, Children’s Division (DFS), Division of Youth Services, schools, Juvenile courts and the Division of CPS.
- Some of it looked like it would. Some of it sent me to the Twilight Zone.
- I kept zoning out on some of your writing. If your legal-eze agrees with the focus member’s comments, then it looks pretty good.
- As a school district employee, participant in one of the work groups, and someone who works with agencies and families in the St. Louis area, I feel that the report does not reflect some of the concerns that are so critical to the families and individuals with disabilities in this area.
- I applaud the work that you are doing and the leadership you are providing to all of us to implement change! Thanks!
- All good ideas...as long as implemented with training and across the regions.
- If a rule is made stick with it!

Some comments were received that represented stakeholder concerns and opinions:

- Understand the rural dynamic and the problems it can create for consumers in rural Missouri areas i.e. transportation
- Let the caseworkers have freedom to coordinate services. This new privacy act hinders this service.

- Yes, [the initiatives will improve access to services].
- Yes, [the initiatives will increase consumer choice and control, and enhance competencies and information].
- Yes, [the initiatives will improve access to services, increase consumer choice and control, and enhance competencies and information].
- I think it is a lot of money and funds for research when someone should work with families receiving services to request more individuals using the system to help implement a workable plan.
- Maybe, [the initiatives will improve access to services, increase consumer choice and control, and enhance competencies and information].
- Make sure if a specific need is identified and money is available that the service is provided.
- Cut down on personnel at the Jefferson City office.
- Use minimum paperwork as possible.
- Yes these initiatives will increase consumer choice and control for families, Children's Division, and the courts that have to make decisions and choices for the children and youth we serve.
- I want to thank you for giving me the opportunity to provide several general thoughts on the report and the best of luck as you move forward with your goals.
- Windows of opportunity close very quickly and the momentum you create today will determine the successes of tomorrow.
- Let consumers have their own staff. Change the outdated Medicaid Resource Limit in this state to the SSI standard. The state would save on this – less time on reinvestigations.
- The timeline Present to July, 2006 (p. 18), will this breakthrough last that long? Maybe the age a child needs to stay in school for transition needs to be expanded. I thought we lived in a country of laws. Does the school have to provide transition services at 14, is it the law? In other states (40), a person eligible for SSI receives Medicaid. Why not Missouri? I guess it makes too much sense to work here. It would be more cost effective and Consumer friendly. The resources limit is older than 30 years. The difference between Missouri's resource limit and SSI is so small.
- Hold incompetent individuals accountable!
- Should be new review for funds. Such as some families have received services for years with no change. New families cannot receive any services at all. I think some families can reduce some services so others can at least access and use some services.
- Problem: for the last 2 ½ years, funding for new programs has been frozen in the St. Louis region. Families and children who need support that was not provided prior to this time are not receiving support.
- I do not see any initiatives that address the inequity of funding in this state. This was a common theme in all of the workgroups in this area, yet was not mentioned in the document. In addition, many initiatives targeted the Kansas

City area specifically. This is unacceptable and again, points to the inequitable funding for programs throughout this state.

Summary of agency/organization responses

The following organizations responded by letter or commentary to the System Breakthrough Report:

MOAIDD:

We appreciate the letter from the Missouri Alliance for Individuals with Developmental Disabilities. The letter asked that the System Breakthrough report be written in plain, people-first language and be presented in a simple short document to assist self-advocates and family members in making the comments.

Response:

The Division acknowledges the complexity of the document and offers assistance by a staff member at any time to assist with understanding and tracking of the project.

MPCDD:

The “Comments and Recommendations” received from the Missouri Planning Council for Developmental Disabilities highlighted several areas. The MPCDD applauded efforts to include many self-advocates and family members from across the state and encouraged parents and self-advocates to be involved in all discussions and decision-making efforts relating to these initiatives as well as other Division taskforces and Management Advisory Teams.

The Council was pleased with the areas of enhancement as outlined in the Independence Plus Grant to increase individuals’ choice and control in their lives.

The Council encouraged state agencies to be proactive in expanding community supports for those individuals desiring to leave the habilitation centers, nursing homes and other congregate settings.

The Council's response indicates that it believes the area of direct care workers competencies and training was under-emphasized. The Council expressed concern about the lack of funding for training and the absence of a career ladder for direct care workers.

Note: The full response can be obtained from the MPCDD c/o Susan Pritchard-Green, Executive Director, Missouri Planning Council for Developmental Disabilities. P.O. Box 687, 1706 E. Elm Street, Jefferson City, Missouri, 65102 (800-500-7878; voice-TT 573-751-8611).

Response:

The MPCDD's response is welcomed. In any way possible, the Division would like to work with the Council on common initiatives within the framework and priorities of the Division and the Council.

In regard to the MPCDD's suggestion regarding expanding community-based supports, the Division has presented a five-year plan to the Mental Health Commission that projects the movement of over 200 people to community-based alternatives in the next 2.5 years. The need to address the structure of the service delivery system was noted in the "Special Issue" section of the System Breakthrough for Excellence report.

MACDDS:

The Missouri Association of County Developmental Disabilities Services (MACDDS) presented a document entitled "Embracing Opportunities" as a response to the Division's draft System Breakthrough for Excellence report.

"Embracing Opportunities" states that "service delivery systems operated at the local level embrace all of the value of choice, person-centered planning, options for self-directed services, and high user satisfaction." The concept promoted in this document "is a flexible state system promoting an expanded county-based service delivery system providing local authority and flexibility that blends state and local taxes and charitable giving, utilizing County Boards and/or their affiliated agencies."

Under "Proposed Strategies," the MACDDS suggests endorsing, promoting and otherwise reducing or eliminating barriers to the continuing formation of state/county partnerships under existing contractual formats.

NOTE: The MACDDS full report can be obtained by contacting Mary Sullivan-Thomas, c/o Community Opportunities, P.O. Box 420, Troy, Missouri, 63379 (636-462-7695).

Response:

The Division currently has a number of contractual agreements with county boards in the State of Missouri. With the special assistance of MRDD's Deputy Director for Community-Based Services, the Division of MRDD and members of MACDDS are working together to agree upon contract language for the intergovernmental agreements now in place or pending.